FACTORS INFLUENCING ADHERENCE WITH ANTI-RETROVIRAL THERAPY FOR HIV POSITIVE FEMALE INMATES

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ABSTRACT

DONNA WHITE ROBERSON: Factors Influencing Adherence with Anti-Retroviral Therapy for HIV Positive Female Inmates

(Under the direction of Catherine I. Fogel)

With advances in medication therapy, HIV has become a chronic illness successfully treated provided the patient is able to achieve adherence with the prescribed anti-retroviral medication regimen. The numbers of new HIV cases each year are increasing in women, especially women of color. Moreover, the rates of infection for incarcerated women are double that of incarcerated men. Incarcerated women frequently come from environments burdened with violence, substance and physical abuse, homelessness, child-care issues and mental illness. Such burdens negatively impact the ability of the women to adhere to the medication plan.

The purpose of this study was to explore incarcerated HIV positive women's beliefs of the barriers and facilitators to ART adherence, the role of healthcare provider relationships with adherence and how issues of medical privacy influence ability or desire to adhere while incarcerated. Through qualitative exploratory, descriptive inquiry, a secondary analysis using a pre-existing set of interviews with HIV positive female inmates was conducted to determine the answers to the research questions. Factors identified influencing ART adherence were the medication line, stigma, the routine, administration choice (directly observed therapy or keep own prescription), a relationship with the healthcare provider, policies within the prison, education and medical privacy.

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CHAPTER ONE

INTRODUCTION

Human Immunodeficiency Virus (HIV) is a viral disease that damages the immune system in such a manner that it can no longer effectively defend the body against opportunistic infections (Ferri, Roose, & Schwendeman, n.d.; Lewis, Heitkemper, & Dirksen, 2004). If left untreated or is inadequately treated, the damaged immune system and subsequent vulnerability to infection leads to Acquired Immunodeficiency Syndrome (AIDS). Specific criteria must be met for a person to be diagnosed with AIDS such as infection with opportunistic organisms (*Pneumocystis carinii* pneumonia), certain cancers (Kaposi's sarcoma), loss of 10% or more of ideal body mass (Wasting Syndrome) and/or severely depleted immune components (CD-4 cell count less than 200) (Lewis, Heitkemper, & Dirksen, 2004).

With advances in medication therapies, HIV infection has become a chronic illness requiring management to prevent transmission to others and reduce the risk of developing AIDS (Rintamaki, et al., 2006; Wood, et al., 2006). Tremendous success managing HIV has been accomplished using Anti-Retroviral Therapy (ART) to reduce viral load and improve CD-4 cell counts (Rintamaki, et al., 2006; Wood, et al., 2006). At the same time, a 95% adherence level to ART is essential to maintain reduced or undetectable viral loads and to prevent the formation of drug-resistant viral mutations (Lewis, Colbert, Erlen, & Meyers, 2006; Spaulding, et al., 2002; Wohl, et al., 2003). A particular concern has been placed on

the issue of medication therapy initiation and adherence (DHHS Panel of Anti-Retroviral Guidelines for Adults and Adolescents, 2006; Rintamaki, et al., 2006).

Simply put, medication adherence is defined as a "proportion of prescribed number of pills taken" (Reynolds, et al., 2004, p. 142). Medication adherence, however, in addition to the number of pills taken, must include whether the medications were taken in the appropriate amounts, with appropriate diet (with food or on an empty stomach) and at the appropriate times (Park & Meade, no date). Recommended ART regimens are often complex, including two or more different drugs designed to target the HIV infection at various stages of replication or growth (DHHS Panel of Anti-Retroviral Guidelines for Adults and Adolescents, 2006).

While HIV rates have stabilized in many populations, rates of HIV are increasing in women, especially women of color (Centers for Disease Control and Prevention, 2004). Although women of African American or Hispanic ethnicity comprised only about 25% of the United States population, they accounted for more than three-fourths of total AIDS diagnoses (Arriola, Braithwaite, & Newkirk, 2006; CDC, 2004). More women of color reside in the Southern United States where HIV rates exceed those of any other region in the country (Aral, O'Leary, & Baker, 2006). Moreover, HIV rates in the incarcerated population are increasing with infection rates in women exceeding those of men (Arriola, Braithwaite, & Newkirk, 2006). The alarming statistics compel nurses to better understand the barriers to and facilitators of adherence for HIV positive women, especially those who are incarcerated.

While nurses need to understand the factors influencing adherence for any patient on ART, understanding is critical for the most vulnerable patients requiring assistance to maintain the necessary high level of adherence, such as incarcerated women during

incarceration and after release from prison. The unique needs of incarcerated HIV positive women have not been adequately explored, therefore, the purpose of this study is to determine what the women view as barriers and facilitators to ART adherence, how a relationship with a healthcare provider affects adherence, and if medical privacy while incarcerated impacts adherence with ART. The following research questions were posed in order to explore HIV positive female inmates' perceptions of ART adherence:

1. What are the barriers and facilitators to ART adherence?
2. Does the relationship with the healthcare provider impact adherence? And if so, how does the relationship with the healthcare provider impact adherence?
3. Does medical privacy while incarcerated (or the lack of) influence adherence? And if so, how does medical privacy while incarcerated (or the lack of) influence adherence?

CHAPTER TWO

REVIEW OF LITERATURE

HIV in women

New cases of HIV infections in women have grown from comprising about 8% of new cases in 1985 to more than 25% of new cases in 2004 **(**Henry J. Kaiser Family Foundation, 2006). Most women are infected at a young age, adversely affecting the long-term health of the woman, care of her children and family, and financial costs of healthcare to the woman and society (Henry J. Kaiser Family Foundation, 2006; Lewis, 2006). Research has demonstrated higher rates of HIV/AIDS in the poor, secondary to social inequities (Arriola, Braithwaite, & Baker, 2006). Rates of HIV are higher in impoverished counties, of which 78% are found in the Southern region of the United States (Aral, O'Leary, & Baker, 2006). The rates of HIV in women living in the Southern United States are twelve times that of the national rate for women (Henry J. Kaiser Family Foundation, 2006). The majority of women becoming infected with HIV are women of African American ethnicity (Arriola, Braithwaite, & Newkirk, 2006; Henry J. Kaiser Family Foundation, 2006).

Women prisoners

Incarceration rates for women are rising at twice the rate of men (Lewis, 2006). The majority of women incarcerated (60%) were responsible for care of children up to the time of imprisonment focusing increased attention on the impact of maternal incarceration on

families, children and future generations (Lewis, 2006). Incarcerated women are more likely then incarcerated men to have been victims of violence and abuse, substance abuse, poor and engaged in sex work for food or drugs (Arriola, Braithwaite, & Baker, 2006; Lewis, 2006). African American and Hispanic women represent a disproportionate number of incarcerated women (Arriola, Braithwaite, & Baker, 2006). The importance of reaching these women before and after incarceration has been emphasized. Working to improve health and living conditions, employment opportunities and community support after release helped improve the health and well-being of the women (Arriola, Braithwaite, & Baker, 2006).

HIV in women prisoners

Prevalence of HIV infections among incarcerated women are roughly double that of incarcerated men (Arriola, Braithwaite, & Newkirk, 2006). Life circumstances tend to be very different for incarcerated women than for incarcerated men because of their higher levels of poverty, increased exposure to violence and abuse, substance abuse, and unstable living conditions. Further, incarcerated women are more likely than incarcerated men to have used sex work to buy food and drugs and thus have greater risk for HIV infection (Arriola, Braithwaite, & Newkirk, 2006). Incarcerated HIV positive women require complex healthcare including treatment and prevention programs for medication initiation and adherence, additional healthcare needs including pregnancy, and the resources needed to maintain a healthier lifestyle upon release (Arriola, Braithwaite, & Newkirk, 2006; Holstad, Dilorio, & Magowe, 2006; Lewis, 2006).

Adherence in general

Adherence is of interest to healthcare providers because adherence to most medication regimens usually improves the health of the person, reduces adverse sequelae from the disease process, and reduces healthcare costs (Johnson, et al., 2005).

Gianfrancesco and associates (2006) reviewing factors influencing adherence with antipsychotic agents, found that poor adherence was associated with severity of illness and side effects from the agent used, especially those with extrapyramidal effects (EPS) and weight gain. Non-adherence has also been linked to lack of medical insurance, substance abuse, and higher doses of medications (Lewis, 2006). Facilitators of adherence were having a close, consistent relationship with a healthcare provider, use of atypical antipsychotics, and use of depot agents (long-acting, less frequently administered medications). Similarly, researchers exploring anti-hypertensive adherence found that a close patient –provider relationship, social support, and monotherapy increased adherence while medication side effects, expense, and inconvenience were barriers to adherence (Bramley, Gerbino, Nightengale, & Frech-Tamas, 2006; Ogedegbe, Harrison, Robbins, Mancuso & Allegrante, 2004).

Adherence to HIV medications

Major barriers to adhere to ART are the expense and complexity of the regimens (Henry J. Kaiser Family Foundation, 2006). Many agents used in ART require three times daily dosing, taking on an empty stomach or with a light meal, avoidance of certain types of foods, and care to avoid interactions with other medications. In July, 2006, a new one-pill combination agent was introduced to the ART market with a projected cost of $1150 for a 30-day supply (Henry J. Kaiser Family Foundation, 2006). Another major barrier is the side

effects associated with most of the agents prescribed, including the new combination pill. ART side effects include gastrointestinal distress, neurological symptoms, and liver damage (DHHS Panel of Anti-Retroviral Guidelines for Adults and Adolescents, 2006). In addition, there are special considerations for childbearing women in prescribing as some agents have teratogenic effects. Considering most women with HIV are of childbearing age (15-44 years of age), agent selection becomes crucial in preventing fetal exposure to a teratogenic agent (DHHS Panel of Anti-Retroviral Guidelines for Adults and Adolescents, 2006). Moreover, women tend to be diagnosed later in the course of the disease which means higher viral loads and greater risk of conversion to AIDS (Holstad, Dilorio, & Magowe, 2006). Women, especially inmates, also deal with what has been identified as gender-unique barriers to ART such as socioeconomic factors, mental illness, substance abuse, physical violence and abuse, and family obligations (Lewis, 2006).

Socioeconomic factors including poverty, unemployment and homelessness can adversely affect a woman's ability to adhere with expensive and complex regimens such as ART. Additionally, women tend to have responsibilities for children and family that decreases their ability to care for themselves (Centers for Disease Control and Prevention, 2001; Holstad, Dilorio, & Magowe, 2006; Holzemer, et al., 2006).

Physical and mental health-related issues also may negatively impact adherence with ART. Incarcerated women are more likely than incarcerate men to have experienced substance abuse, physical violence and depression; in addition, many have traded sex for money or drugs (CDC, 2001; Fogel & Belyea, 1999; Lewis, 2006). Further, in general, women have not received as many resources for HIV/AIDS healthcare as have men, especially while incarcerated (Lewis, 2006; Zaitzow, 1999.) Smaller numbers of female

inmates have resulted in fewer, smaller facilities for women, often far away from family. While the need for equivalent services, regardless of gender, has been acknowledged, parity does not exist today any more than it did in 1999 (Lewis, 2006). Compared to men, there are greater healthcare needs for women, especially if pregnant. The need for other women-specific care makes provision of healthcare to female inmates difficult despite federal mandates to provide care equivalent to that available outside of prison; for example, the expense and space requirements for gynecological care (Lewis, 2006). Zaitzow (1999) found that prisons were ill equipped to handle female inmates when substance abuse was coupled with mental illness. Further, Zaitzow (1999) identified that HIV-infected female inmates required counseling to cope with the double-stigma of being incarcerated and being HIV–positive and that education regarding HIV acquisition and transmission was lacking. Issues identified by correctional administrators centered on whether to screen all incoming inmates for HIV, how to house those with HIV/AIDS, and the financial burden of providing long-term and expensive healthcare to the HIV positive female inmate (Zaitzow, 1999). Lewis (2006) described a continuation of much of the same problems, seven years after Zaitzow. In addition to the unique health care needs of incarcerated women as opposed to incarcerated men, Lewis (2006) also found incarcerated women tended to use sick call more than incarcerated men and incarcerated women are more likely to be further victimized during and after incarceration (Lewis, 2006).

Stigma

Another barrier to adherence with ART is stigma. Stigma plagues HIV positive women whether they are incarcerated or not. Fear that others will assume her HIV status from the medications she takes or the healthcare visits she makes may cause the woman to

hide her diagnosis and potentially delay or refuse care (Holstad, Dilorio, & Magowe, 2006; Lewis, Colbert, Erlen, & Meyers, 2006; Sandelowski, Lambe, & Barruso, 2004; Spaulding, et al., 2002). Holstad, Dilorio, and Magowe (2006) found that women hid their diagnosis more than their male counterparts, inadvertently setting themselves up for social isolation and increasing their vulnerability to adherence failure. Privacy is necessarily limited in prison, and may result in reluctance to access healthcare by an inmate, thus creating a situation whereby the woman refuses care to avoid others learning her medical diagnosis (Frank, 1999; Stoller, 2003; Rosen et al., 2004; White, et al., 2006; Wohl, et al., 2003.) Furthermore, the healthcare clinic may be a considerable distance from the cells or dormitories in which inmates reside, making the physical movement to obtain care difficult at times (Stoller, 2003).

Facilitating adherence in the female inmate with HIV

Clearly complicated issues impact the ability of the HIV positive woman to adhere with ART and adherence becomes further complicated by incarceration. The Centers for Disease Control and Prevention (2001) called for innovative programs that use special screening tools designed to assess the female inmate's risk, provide drug abuse treatment custom-made for the woman who has been victimized or is mentally ill, and consideration for the pregnant woman and ART agents chosen to avoid teratogenic effects. The Health Link program in New York City offered case management to reduce HIV risk behaviors during prison and for one year after release (CDC, 2001). Although not limited to HIV-positive women, the California Centerforce Parent Project for Women provides many services to support women inmates and their families. Centerforce offers parenting classes and coping strategies to handle recovery, abuse, parenting while incarcerated and communication

training to improve anger management and interactions with children. Such counseling and skill building programs address many of the issues women have with being ART adherent and could improve adherence and the overall well-being of the released woman (CDC, 2001; Centerforce, 2006).

The AIDS Counseling and Education (ACE) Peer Education Program is an inmate organization started in New York State's largest female correctional facility (CDC, 2001). ACE works with community programs to continue the education and support offered while incarcerated when women are released. Others have called for women-specific outreach programs that link services and counseling received while incarcerated to the communities to which the women subsequently return (Mostashari, Riley, Selwyn, & Altice, 1998; Palepu, Tyndall, Chan, Wood, Montaner, & Hogg, 2004; Spaulding et al., 2002; Springer, Pesanti, Hodges, Macura, Doros, & Altice, 2004; Stephenson, Wohl, Golin, Tien, Stewart, & Kaplan, 2005.) A case management approach seems appropriate for most of the needs identified in the studies reviewed, but to plan care in an economical and effective manner, it would behoove nurses to understand the needs as identified by the women living with the problem.

How supported the woman feels, level of trust in the efficacy of ART and relationships formed with healthcare providers impact adherence for women who are HIV positive (Centers for Disease Control and Prevention, 2001; Holstad, Dilorio, & Magowe, 2006; Lewis, 2006). A unique older study conducted by Mostashari, Riley, Selwyn and Altice (1998) found HIV positive female inmates who had trust in the efficacy of ART, as opposed to those who did not trust the efficacy of ART, were more accepting of therapy while imprisoned. Further, satisfaction with healthcare in the correctional facility and having a satisfying relationship with a prison healthcare provider were correlated with an increased

acceptance of ART. Women in this study were more likely to have started ART while in prison; and, if the prison healthcare system had services designed to meet the needs of female inmates, women were more accepting of ART. Alleviating social isolation, especially on release, was thought to improve adherence rates (Mostashari, Riley, Selwyn, & Altice, 1998). The importance of the concept of support for HIV-positive women prisoners has been shown to increase acceptance of beginning ART therapy; however, how female inmates define support in relation to ART adherence has not been explored.

Several studies have been conducted to determine the relationship between ART adherence and recidivism (Palepu, Tyndall, Chan, Wood, Montaner, & Hogg, 2004; Springer, Pesanti, Hodges, Macura, Doros, & Altice, 2004; Stephenson, Wohl, Golin, Tien, Stewart, & Kaplan, 2005). Researchers have found that imprisonment has positive outcomes of higher CD4 counts, low or undetectable viral loads, and high rates of adherence. Springer and associates (2004) found that almost one-third of returning inmates who had previously high CD4 counts and low viral loads at release, had significantly lower CD4 counts and elevated viral loads leading to poor health outcomes at reincarceration. Further, prison ART and HIV care was found to be quite successful in meeting treatment outcomes, but lack of long-term post-release programs essentially placed the released inmate back into the environment that had made ART adherence difficult or impossible before incarceration (Springer, Pesanti, Hodges, Macura, Doros, & Altice, 2004). Palepu and associates (2004) documented similar findings within their prison system in British Columbia. Inmates were provided structured and successful ART via the prison healthcare programs achieving improved CD4 counts and reduced viral loads as well as high adherence rates; however, upon release, these inmates lacked the resources and abilities to maintain the high level of

adherence (Palepu, et al., 2004). Stephenson and colleagues (2005) determined that re-incarcerated participants had lower CD4 counts and higher viral loads than did participants who were continuously incarcerated. It was not known if adherence was better or worse for those re-incarcerated, but it was clear there was a need for comprehensive discharge planning to ensure quality care continued upon release (Stephenson, et al., 2005). Although these three studies were conducted with male inmates, the impact on health status of female inmates is thought to be similar. These research findings indicate that the need for community programs and discharge strategies to maintain adherence is important; however, equally important is more information with which to design interventions to address the unique needs of women prisoners.

Lack of medical privacy has been suggested as a reason for inmates not seeking HIV treatment (Frank, 1999; Rosen, et al., 2004; Stoller, 2003; Wohl, et al., 2003). Although prisoners are entitled to the certain rights under the United States Constitution, these rights are limited in many instances (Palmer & Palmer, 2004). The Eighth Amendment to the US Constitution provides citizens protection from cruel and unusual punishment. It is under the Eighth Amendment that most claims for medical care while incarcerated are filed. The landmark case, *Estelle V. Gamble* 429 U.S. 97 (1976), addressed inmate rights to medical care and was the first to attempt to define exactly which rights inmates hold while imprisoned. The lower federal courts have used *Estelle V. Gamble* to ensure each prisoner has the right of basic medical care (Glaser & Greifinger, 1993).

The Fourteenth Amendment to the Constitution has several sections, but for the topic at hand, it guarantees due process and equal treatment regardless of race, gender or creed (The 14th Amendment to the Constitution, 1997). Court decisions have expanded the 14th

Amendment to include an individual's right to privacy. Inmate's rights to privacy, medical or otherwise, are quite controversial and have been the subject of many lawsuits and court decisions. Inmates with HIV or AIDS have sued for medical privacy rights many times. In *Hudson V. Palmer* 468 US 517, 526 (1984), the court concluded prisoners have NO right of privacy but are to be free from cruel and unusual punishment. The freedom from cruel and unusual punishment included not teasing or otherwise punishing someone for being HIV positive. Additionally, the judges ruled prison officials could not threaten to reveal medical history for coercion or disclose irrelevant medical history. In *Anderson V. Romero* 72 F.3d 518 (1995), Chief Judge Posner stated that although the right to medical privacy evolved from common law rather than US Constitution, inmates cannot be punished because of HIV status. Judge Posner remarked that some confusion was added to the legal fray when, in *Austen V. Pennsylvania Department of Corrections* 876 F. Supp 1437(1995), the plaintiff and defendants agreed to use universal precautions for all inmates and that the practice of disclosing HIV status as a means of protecting the health of the prison population would cease. According to Posner, the court ruling in this case merely supported the settlement rather than providing an opinion granting a legal right to medical privacy (as it is sometimes applied.)

The US Court of Appeals, Third Circuit, heard *Doe V. Delie* 257 F.3d 309 (2001) where Doe believed his medical privacy rights had been violated when a nurse discussed his care in a prison clinic with the examination room door open, revealing his HIV status to all in the clinic area. Judge Roth opined that, under the 14th Amendment, there is a right to medical privacy but that it is "subject to legitimate penological interests" (p. 311). Judge Garth dissenting with this opinion wrote that there was no right to medical privacy for

inmates in the Constitution. Dissention between the judges is common in these cases. Judge Roth said the volume of dissenting opinions resulted in a lack of clear legal definitions as to the constitutionality of medical privacy rights of inmates.

Summary

Factors that have been identified as influencing adherence to ART therapy by HIV positive persons to ART therapy include stigma, religious beliefs and practices, perceived social support and role demands in both women and men (Edwards, 2006; Lewis, Colbert, Erlen, & Meyers, 2006; Parsons, Cruise, Davenport & Jones, 2006; Rintamaki, et al., 2006). Many HIV-positive individuals fear the stigma associated with HIV to the point they do not disclose their HIV status and avoid seeking care to prevent others from learning their health status (Rintamaki, et al., 2006). Supportive family members and being the mother of younger children helped women adhere; however, feeling stigmatized, unloved or those caring for a spouse with HIV were barriers to ART adherence for HIV-positive African American women (Edwards, 2006). Prison necessarily blocks the benefit of mothering children and fosters a sense of stigma (Holstad, Dilorio, & Magowe, 2006; Lewis, Colbert, Erlen, & Meyers, 2006; Sandelowski, Lambe, & Barruso, 2004; Spaulding, et al., 2002). With confidence in the efficacy of ART and strong relationships between the patient and their healthcare provider, adherence was enhanced for men and women (Lewis, Colbert, Erlen, & Meyers, 2006). The value of community programs in improving adherence and general health of women has been identified (CDC, 2001; Mostashari, Riley, Selwyn, & Altice, 1998; Palepu, Tyndall, Chan, Wood, Montaner, & Hogg, 2004; Spaulding et al., 2002; Springer, Pesanti, Hodges, Macura, Doros, & Altice, 2004; Stephenson, Wohl, Golin, Tien, Stewart, & Kaplan, 2005).

Limited research has been conducted focusing on a population with growing rates of HIV, incarcerated women. Mostashari, Riley, Selwyn and Altice (1998) conducting the only study to date that addressed the unique needs of HIV positive female inmates, found trust in the efficacy of ART and the prison healthcare improved acceptance of ART therapy. However, with the changes in ART regimens and introduction of new agents, it is plausible to assume that the barriers and facilitators to adherence may have changed. The importance of social support while incarcerated has been emphasized (CDC, 2001; Holstad, Dilorio, & Magowe, 2006; Lewis, 2006). Lack of medical privacy has been shown to be a barrier to adherence to ART while imprisoned; however, the right to medical privacy while incarcerated continues to be a contentious topic. By denying medical privacy to inmates, prisons may be inadvertently reducing the ART adherence rate and increasing the risk of complications to the inmate and spread of the disease upon release in the community. Qualitative research describing the barriers and facilitators for ART adherence viewed by HIV positive female inmates, including issues of medical privacy, is needed. Additionally, the views of HIV positive female inmates of relationships with prison healthcare providers in relation to ART adherence require exploration.

In summation, the factors identified in the literature as barriers affecting medication adherence included stigma, religious beliefs, and responsibilities for childcare (unsupported). The factors identified in the literature as facilitators affecting medication adherence were social support, responsibilities for childcare (supported,) community programs, relationships with healthcare providers and medical privacy. However, the deficiencies identified in the research studies reviewed included an absence of studies with female inmates, the barriers influencing adherence were those found upon release versus those while incarcerated, studies

indicating the structure of prison healthcare improved the health of inmates were on HIV positive men and finally, the needs of HIV positive incarcerated women have not been adequately explored.

Clearly, adherence with ART is vital to maintaining the health status of the HIV positive female inmate. The purpose of this study was to explore incarcerated HIV positive women's beliefs of the barriers and facilitators to ART adherence and the role of support, healthcare provider relationships and issues of medical privacy as they relate to adherence while incarcerated.

CHAPTER THREE

METHODOLOGY

Most readers are familiar with quantitative research whereby phenomena are measured and results are calculated using particular statistical analyses. Qualitative research, however, is used to explore subjective thoughts, emotions and perceptions in a manner a numerical analysis would never provide (Thorne, Kirkham, & MacDonald-Emes, 1997). Qualitative research allows the researcher to explore and describe the phenomenon of interest using the actual words from those who live the phenomenon (Parse, 2001; Sandelowski, 2000). While adherence with ART has been studied in HIV-positive populations, the unique facilitators and barriers to ART adherence and the experience HIV-positive female inmates have had with adherence are not well understood. Through qualitative exploratory, descriptive inquiry, a secondary analysis using a pre-existing set of interviews with HIV positive female inmates was conducted to determine the answers to the research questions. My experiences as a research assistant at the women's prison have made me intensely aware of the problems facing female inmates. Participation in an interventional study designed to prevent HIV acquisition in incarcerated women has shown me that many women have limited knowledge of their health and lack strategies to preserve their health. I have found the women to be motivated to learn and quite vocal about their needs. My personal knowledge of the setting is helpful in that I have a better understanding of how medications are administered in prison than someone who has never worked in the prison setting. Conversely,

my personal knowledge has the potential to be a disadvantage as I have preformed opinions regarding medication administration in the prison system. My awareness of personal underlying assumptions was an important consideration during the reflective process of the analysis.

The goal of an exploratory, descriptive qualitative study is to allow the participants living the phenomenon to answer the research questions. Their views of past, present and future are invaluable to the nurse who seeks better understanding of a unique person or group of persons and their experiences (Morse, 1994). With a qualitative descriptive design, the research questions form the conceptual framework for the study (Parse, 2001). One of the assumptions of qualitative descriptive research is that "patterns and themes surface through intense study of phenomena" (Parse, 2001, p. 57). Qualitative descriptive inquiry may be exploratory or a case study approach. The goal of this study was to explore and describe barriers, facilitators, roles of healthcare provider relationships and issues of medical privacy as they influence ART adherence using the participants' perceptions. The description was planned to be close to the original data, with little inference, as the aim was to provide a clearer understanding of the phenomenon based on those who live the experience rather than an interpretation of the experience from an outsider's viewpoint (Parse, 2001; Sandelowski, 2000). As stated by Sandelowski (2000, p. 335,) in qualitative description "language is a vehicle of communication, not itself an interpretive structure that must be read." The use of qualitative descriptive analysis clarifies and defines important components of medication adherence including *who*, *what* and *how* adherence is influenced.

With this existing data set, the views of the interviewed women described adherence with ART while in prison. Interviews are a valuable inquiry tool to reveal the phenomenon of

interest. The analysis of interview data, which is viewed as the experiences of the subject, may be descriptive, interpretive or both (Morse, 1994). In the case of this study, a qualitative descriptive approach was used to ensure the participants' views were represented as accurately as possible. Interview questions were not necessarily coded based upon inferences, but rather, read and re-read until the "essence" of the answer provided was known and themes could be identified (Miles & Huberman, p. 8, 1994).

The interview is a common cornerstone of qualitative research (DiCicco-Bloom & Crabtree, 2006). Most researchers utilize a semi-structured approach to questioning participants; however, structured and open approaches also are used (Clarke, 2006; DiCicco-Bloom & Crabtree, 2006; Donalek, 2005). Issues of power between the interviewer and interviewee can be balanced through choice of location (such as a familiar clinic as in this study), displaying sensitivity to the topic of the interview (use of nonjudgmental tone) and matching the gender of the subject with that of the interviewer(as was done in this study) (Clarke, 2006).

As recommended by DiCicco-Bloom and Crabtree (2006), the interview structure for this study was conducted first using basic, non-threatening questions followed by questions focused more on the research interests. The interviewer paused to allow the participant ample time to respond, summarized the given response and asked for further elaboration with each question. Furthermore, the interviewer closed each interview by asking if the participant had any other information to share and maintained a relaxed tone throughout. Keeping the interviewee relaxed is important to provide the person time and permission to speak (Clarke, 2005; DiCicco-Bloom & Crabtree, 2006; Donalek, 2005). When the interviewee became

distressed, the interviewer remained quiet, allowed the woman to regain control, and moved away from the topic.

Departing from the planned question in the event of obvious emotional distress is desired (Clarke, 2005; DiCicco-Bloom & Crabtree, 2006). The research assistant conducting the interviews consistently following the same question format with each participant and was meticulous in summarizing their statements to ensure the answer conveyed was the intended response by the woman. When listening to the tapes, I noted the women readily responded to the interviewer's questions and rarely hesitated, unless crying or considering their response.

Secondary analysis in qualitative research

Secondary analysis is well-recognized as a valuable tool in quantitative research and has gained in popularity in qualitative research (Heaton, 2004). When certain elements of suitability are met, secondary analysis of qualitative data is an appropriate and viable means of descriptive study (Heaton, 2004; Hinds, Vogel, & Clarke-Steffen, 1997; Szabo & Strang, 1997; Thorne, 1994). Advantages and disadvantages of secondary analysis are discussed as they relate to qualitative inquiry and this study.

To determine the suitability of secondary data for qualitative analysis, Hinds, Vogel and Clarke-Steffen (1997) recommend the following key components: (1) full access to the interview transcripts, tapes and field notes; (2) consultation with the principal investigator; (3) complete responses to the interview questions of interest; (4) verification of transcription accuracy; and (5) preservation of the anonymity of the subjects. The interview transcripts used in this study were found highly suitable using the guidelines above. I had full access to and transcribed the taped interviews. I had copies of the field notes the interviewer made during each interview. The original principal investigator, Dr. Becky White, participated in

the dissertation committee. While some answers were difficult to hear on the tapes, the detailed field notes supplied insight into the nature of the participant's response and therefore provided comprehensive interview transcripts. The transcripts and tapes were reviewed by an accomplished nursing researcher, Dr. Cathie Fogel for accuracy. Finally, I had the random identification numbers for each tape with no ability to connect the participant's identity to their interview, thereby protecting the confidentiality of each participant. I assigned pseudonyms to make the interviews more personable for both the reader and myself, but any similarity to the participant's real name would be coincidental. Meeting the demands of guidelines such as Hinds, Vogel and Clarke-Steffen's (1997) satisfy tests of rigor such as consistency, neutrality, truth value and fittingness (LoBiondo-Wood & Haber, 2006; Szabo & Strang, 1997).

As stated before, if the research questions are close to the original questions, secondary analysis can be a viable option for a more in-depth exploration (Hinds, Vogel, & Clarke-Steffen, 1997). A major disadvantage of secondary data analysis is not being able to clarify or explore comments the woman made; however, this does not negate the importance of what is said. For many years, authors have viewed the prison as an opportunity to educate and treat a group of people that are often difficult to reach (Blanco, Perez & March, 2005; Crosland, Poshkus & Rich, 2002; Glaser, & Greifinger, 1993; Spaulding, et al., 2002; Wohl, et al., 2003). Secondary analysis has the benefits of using data already obtained from those difficult to reach people, avoiding further burden on subjects, allowing research on sensitive topics and utilizing data from a primary work that was not otherwise used (Heaton, 2004). As research funding is diminishing, the convenience and cost-effectiveness of re-use of data is an attractive option (Szabo & Strang, 1997). Finally, because the data were collected

recently, the validity of the findings for current audiences and use is appropriate (Hinds, Vogel & Clarke-Steffen, 1997).

Sample

The data set consisted of 12 individual interviews of HIV-positive women prisoners. The participants were purposefully selected from a sample of HIV positive women inmates who were prescribed ART either by directly observed therapy (DOT), keep own prescription (KOP) or both. These women were selected because they were likely to have answers to the research questions of interest (Miles & Huberman, 1994). Such purposeful sampling is important in descriptive studies to ensure adequate representation from those who live the phenomenon to be studied (Sandelowski, 2000).

A single female research assistant, unaffiliated with the prison or the prison HIV clinic approached every woman visiting the HIV clinic during the recruitment period from November 2004 through March 2005. The HIV clinic was held twice per month with a total of seven clinics held during the recruitment period. Approximately 20 women were seen at each clinic session. . Approximately 70 HIV positive women were seen at least once during the recruitment period. The research assistant was able to recruit and interview during all seven clinics and provided the study description and written informed consent. There were no monetary or tangible reimbursement provided the participants in accordance with prison policy. The women who declined to participate did not want to use their time for the interview. Those who agreed to be interviewed met the inclusion criteria requiring the participants to be receiving ART therapy and be able to speak English. According to Morse (1994) and Sandelowski (1995,) twelve participants are more than an appropriate sample size for descriptive qualitative inquiry, given there is sufficient data from the sample to answer

the research questions. Table 1 summarizes the demographic information on the participants as well as their HIV and ART histories.

Table 1:

Demographics, HIV and Anti-retroviral (ART) History

Name	Age	Ethnicity	HIV +	Time on ART	ART Method
Maria	22	Hispanic	22 months	17 months	KOP*
Lisa	34	African American	4 years	2 months	DOT*
Laura	34	Caucasian	2 years	1 month	KOP
Monique	35	African American	9 years	1 year	KOP
Kristie	38	Caucasian	15 years	4.5 years	KOP
Carmen	39	Hispanic	15 years	15 years	DOT
Barbara	39	African American	4 years	2. 5 years	KOP
Jackie	40	African American	13 years	3 months	KOP and DOT
Dorothy	41	African American	4 years	2 months	KOP and DOT
Jane	41	Caucasian	13 years	2 years	DOT
Janet	42	Caucasian	13 years	5 years	KOP
Angela	45	African American	2 years	2 months	KOP
					*KOP -Keep own prescription *DOT-Directly Observed Therapy

Note: none of the women had taken ART continuously except while incarcerated

Data collection

The interviews were conducted at a large state women's correctional facility from December 2004 through March 2005. The interviews were conducted in a private room at the prison health clinic. The interviewer recorded the interviews with each participant using a micro-cassette tape recorder. The subjects signed informed consent and those consents remain with the original principal investigator. Each participant was informed, through the signed consent form, that their information could be used without an expiration date, and that they would be identified by a study number rather than by name. They were told their health information would be protected, but that those involved in the study would have access to their information. Furthermore, the participants were told their interview would take place in the privacy of the clinic where they could speak freely. The women were notified within the consent form that the prison officials would not participate in the administration of the study and that those officials would not be privy to their responses. The only circumstances where the confidentiality of the interview might have been breached were if the inmate threatened suicide, escape or injury to another person. The original purpose of the study was to discover how HIV positive female inmates perceived medication therapy in prison and to find ways to enhance adherence. The secondary analysis of this data set is very similar to the original intent and is not in conflict with the purpose as stated on the original consent form (Hinds, Vogel & Clarke-Steffen, 1997).

During a preliminary review of the transcripts, I determined there was ample information from the subjects to conduct a descriptive qualitative analysis based on the completeness of responses to interview questions that pertained to the research questions

in my study. The information obtained describes what the women perceived as barriers and facilitators for ART adherence in the prison system, how their relationship with prison healthcare providers influenced how the women felt about adherence and finally, how medical information privacy (or the lack thereof) while incarcerated affected adherence for the women.

Data management

The interview micro-cassette tapes were re-recorded to digital wave files prior to transcription. The digital files are stored on my personal computer that is only used by me and is password protected. The original transcript files are also stored on the same computer. Hard copies of the transcripts, logs and copies of the original interviewer's field notes are stored in my private office, locked in a filing cabinet. A copy of all files including versions of the proposal for the study and this dissertation are on a flash drive which is locked as the hard copy files when not in use. One additional disk with transcripts and first draft of the dissertation were given to Dr. Fogel, dissertation chair, for review. The original consent forms, micro-cassettes and field notes are in the possession of Dr. Fogel.

The final transcripts were typed using Microsoft Word ™ and formatted using double-spacing in the body of the text with a two-inch margin on the right side of the page for coding and note-taking. Available for analysis were 120 pages of transcripts and the 18 page interview form with field notes and interviewer comments for each participant. The interview template was created by Dr. Catherine I. Fogel and Dr. Becky White based on their combined years of experience with female inmates, prison healthcare and HIV adherence. A blank interview template may be found in Appendix I.

Having the data sources readily at hand eased the analysis process. I noted the potential uses of a computer program to assist in data management; however, I wanted to create hand-written notations, categories and codes to improve my immersion in the interviews and therefore did not use any commercial analysis computer programs.

Data analysis

The secondary analysis used for this qualitative exploratory, descriptive study was a valuable tool to avoid loss of precious transcripts elicited from a difficult to reach population who were discussing a sensitive subject. Descriptive analysis was used to determine the answers to the research questions and describe major themes expressed. Parse (2001) suggested the researcher conduct data analysis for qualitative descriptive methods by reading the transcripts while listening to the audio recordings and reviewing field notes and this suggestion was used for this study. With the research questions as a framework of inquiry, the data were first categorized based on the research questions and then themes were identified within each category as described below.

Using techniques in secondary analysis as described by Szabo and Strang (1997), I was able to capitalize on the convenience and cost-effectiveness found when using an existing data set. Use of the data set also allowed exploration of the research questions without subjecting the participants to further emotional distress discussing HIV and ART adherence, further, no additional subjects from this difficult to reach population had to be recruited (Szabo & Strang, 1997). Admittedly, limitations of secondary qualitative analysis had to be considered in that there was no control over the data collection process and allowances had to be made for flexibility in analysis to ensure adequate and accurate descriptions were reported.

Steps during the analysis process were taken to compensate for the disadvantage of not collecting one's own data. The work of analysis was conducted in an evolving manner that remained flexible throughout the secondary analysis (Szabo & Strang, 1997). As in the case of this study, the ability to transcribe the tapes personally aided the researcher in hearing the emphasized words, the pauses and dramatic affects the speaker used to convey answers to the interview questions. Following the example of Szabo and Strang (1997), I made notations when transcribing of pauses, crying or laughing. Furthermore, being able to return to the tapes during analysis maintained the sense of presence in the interviews and further improved the validity of the findings. As recommended by Poland (2002, pp. 629-649), repeated reviewing of the tapes was important to ensure the quality of the transcription of this data, therefore, I listened and re-listened to the tapes throughout the entire data analysis process. I kept a record of thoughts and reflective consideration in a journal. This journal was begun based on suggestions from both Szabo and Strang (1997) and recommendations made in a qualitative analysis course taught by Dr. Marguerite Sandelowski for the purposes of tracking my evolution of ideas and analysis techniques.

The data analysis began with a review of the transcripts. Mason (2004, pp. 148-150) described the process for examining data beginning as a literal read for the purpose of organizing the responses into categories based on the research questions (i.e. barrier, facilitator, healthcare provider comment, medical privacy comment). This process required some interpretive consideration as the words "medical privacy" was not used by the women. I had to read and determine if the woman's comment could be interpreted logically as one referring to privacy. My familiarity with the setting provided insight to

many of the comments about the prison setting and aided in the categorization. As the transcripts were read and tapes reviewed, the choice of words and phrasing clarified the woman's response to questions.

As I categorized responses based on the research questions, I kept a flow sheet where I would mark the number of times a certain phrase or idea was expressed, i.e. dislike of waiting. When it became apparent a response was repeated in a single interview, or echoed in the different women's interviews, I again re-read the individual responses and coded based on the main gist of the responses. For example, comments about not wanting others to know their HIV status were coded as stigma under the category "barriers" and as an indication for privacy. Counting common phrases or words allowed me to begin the establishment of codes within the categories as I read. Additionally, counting was employed as a means to avoid discounting those who may not have been as verbose as others and to establish any patterns or recurrences (Sandelowski, 2001). Counting supports the representation of the data as it is spoken and reported (Sandelowski, 2000). The use of counting also aids the researcher in categorizing responses in a logical manner, such as chronologically or, as with this study, by prevalence of remarks (Sandelowski, 2000). Furthermore, the creation of logs organized content, provided a record of thoughts, and tracked the transition of ideas during the analysis (Mason, 2004; Rodgers & Cowles, 1993). Since I did not create field notes during the interviews (as I did not conduct them), my notations while listening to and reading interviews became a set of special field notes unique to secondary analysis (Hinds, Vogel, & Clarke-Steffen, 1997; Szabo & Strang, 1997). Additionally, the notes I made reminded me of emphasis and phrasing that may not have been clear in the written

transcript. Maintenance of an audit trail, as described by Morse (1994), Miles and Huberman (1994), and Mason (2004) was necessary to ensure each interview was examined in a similar manner (Szabo & Strang, 1997). It has been said that validation of findings from a secondary analysis can be ensured by reviewing themes with the primary researcher (Szabo & Strang, 1997). Dr. Becky White, the original primary researcher, reviewed the findings from this study.

Processes for analysis by question

To make the analysis more manageable, I considered each research question separately as I read each of the interviews, making logs and notes based on answers to the specific question. While reading, I literally marked the front page and line in the transcripts that had answers to my other questions, but primarily focused on the answer to the question at hand. This type of analysis also further increased my submersion in the data as I returned repeatedly to the transcripts and tapes as necessary (Szabo & Strang, 1997). I then had four written logs with categorized information for each research question, considering the first question about barriers and facilitators to adherence as two questions.

For the first question searching for the women's perceptions of barriers and facilitators to adherence with ART in prison, I made a log for barriers and a log for facilitators. As I was reading, it became apparent the responses to questions related to what changes the woman recommended for medication administration in prison were directly linked to barriers and facilitators; therefore, I made a log outlining their suggestions. To illustrate, I found five of the women stated KOP was best way to

administer ART when they were asked what changes should be made. Of those, two received their meds via DOT, two were KOP and one had both administration styles.

In order to determine barriers identified by the women, the entire individual interview was read, then re-read with a focus on answers to questions such as "Tell me about taking medications in prison," "Do you ever have difficulties getting medications in prison," and "Do you ever have difficulties taking medications in prison." To describe the facilitators discussed by the women, I re-read the interviews, then focused on answers to questions such as "Tell me about taking medications in prison," "Are there things that make it easier for you or help you get your medications in prison," and "Are there things that make it easier for you or help you take your medications in prison." In this manner, the questions from the interview guided the initial analysis. As I moved through the analysis, I would determine some responses expanded on the questions and would place these comments in appropriate categories. Occasionally, some women had responses that could be placed in more than one category, which I did.

It is important to define how the researcher extracts phrases or terms that are taken to be equivalent expressions of the obvious word (Mason, 2002). I extracted segments of the interview where the subject specifically used the words "line," "waiting" or "DOT." Use of the word "line" exclusively meant the medication line. The use of the term "DOT" implied the medication line because a nurse or correctional officer watches the inmate take the medication and therefore, the inmate waits in a medication line for DOT. I also considered using the word "waiting" to be an observation of the line as I have observed inmates in this setting, who are waiting, do so in lines – usually standing or leaning against a wall.

In order to describe the women's perceptions of the connection between relationships with healthcare providers and adherence, I focused on questions in the interviews pertaining to support persons, aspects that helped with medications and hindered medications, the recommended changes in medication administration and comments about health. As each interview was read, any mention of talking with a nurse or doctor was highlighted and noted in the log. It is important to note that although the inmate may say the word "nurse," many who dispense medications are medication technicians and are not trained or licensed nurses. Eleven of the twelve women made remarks about nurses and doctors in the prison. Four of the eleven also referenced the how relationships with officers influence adherence. From personal experience in the prison setting, I know the officers are instrumental in permitting the inmate to move across the prison campus. During some instances, an officer may also have to help with medication administration. For this reason, I included comments about the officers with the research question of how relationships with healthcare providers affect adherence.

Descriptions pertaining to the research question of how medical privacy influences adherence with ART in prison was more elusive. Two of the twelve women specifically mentioned privacy when discussing medication administration in prison. A search for statements where the woman was referring to privacy ensued. For example, Maria, who had been on ART for 17 months, liked having KOP. She said KOP avoided the line and "they don't know what all I'm taking." I selected such comments as illustrations of privacy with medications.

CHAPTER FOUR

RESULTS

The words of the women living with HIV and ART while incarcerated provided the necessary description to answer the research questions. All women interviewed identified both barriers and facilitators for adherence. Most spoke of a relationship with one or more prison healthcare providers or correctional officers. Although only two women mentioned the word “privacy” specifically, much was said that referred to privacy issues while incarcerated. The words of the women are plain-spoken and often spoken with emphasis. Additionally, when the women spoke of the dorms, the med call or lock down, I had experience with their facility and understood what they were speaking of. For example, during severe weather, no one can move about the campus of the prison. I spent an hour in the auditorium beyond my set time due to lock down from a severe thunderstorm.

Although Mason (2004) warns that standardized questions may result in standardized responses, many of the women in this study, who I suspect are rarely asked their opinion, explained or offered more information than the question asked. For example, as the interviews were reviewed several times and then discussed with other researchers, it became apparent that the women in the study had definite ideas about the medication line and how HIV medications are administered. This recurrent conversational thread about the medication line was not solicited, but rather was volunteered as questions about how the inmate received their medication were asked. The women were interviewed separately and did not overhear

each other's answers, yet common terms were used. The recurrence of words or a topic suggests its importance (Mason, 2004).

Barriers to adherence

The medication line, where DOT takes place, was perceived as a barrier to adherence. The medication line was described as a source of frustration because of long waits, as a vehicle for stigma, and the means by which medical privacy was lost. Jane, a 41-year-old Caucasian woman on ART, this time for 6 months, called waiting in the line a "hassle." The women observed the medication line was where other inmates and the officers would make assumptions about a woman's HIV status based on her presence in the line and the number of medications she takes. Dorothy, a 41-year-old African-American woman who been on ART for just 2 months, was the most vocal about the medication line. Dorothy discussed how waiting, dealing with inmates breaking in line, and the stigma of taking larger numbers of medications made taking ART difficult. She said, "You know, the inmates assume HIV if you take a lot of medicines. You could be a diabetic."

Those who did not have to obtain their ART medications from the medication line also had opinions about problems with the line. Maria, a 22-year-old Hispanic woman on ART for 17 months, felt KOP afforded her an opportunity to be in control and avoid the line. When asked what to change about medication administration, Maria suggested all women do KOP and "change the line." Kristie, a 38-year-old Caucasian woman who had been HIV positive for 15 years and using KOP, said waiting to receive the medication made it more difficult to receive and take the therapy. She preferred taking the medications herself with no waiting. Janet, a 42-year-old Caucasian woman who had

been HIV positive for 14 years and on ART for about 5 years, liked KOP because with DOT, the person was not sure when they would get their medications.

Jane recognized the structure of DOT as helpful to ensure adherence, but waiting was problematic. She described a situation where she was waiting for an appointment and missed her medication call (med call). She had to wait for the next med call to get her medications. Jane wanted more personal control and less waiting for medications. Angela, a 45-year-old African American woman who had had HIV for 2 years, just started ART 2 months prior to her interview. She liked KOP because it avoided the line and it let her take her medications herself. Barbara was a 39-year-old African American woman HIV positive for 4 years and receiving ART by KOP. Barbara agreed with Angela's statements. "I like taking my medications myself and I like there is (sic) no lines." The majority of the complaints about the medication line were centered on long waits, with additional concerns of lost privacy and stigma by virtue of one's presence in the line.

Dorothy talked about the line as an open assumption from other inmates and prison staff of a person's HIV status. Angela and Dorothy both commented on being treated "badly" when correctional officers and other inmates assumed they were HIV positive. Angela also complained the white bottle medications come in indicates HIV to other inmates. She remarked, "…even the officers, the inmates, don't understand about HIV, but the officers don't treat you right, mean, because of HIV." Janet described another barrier to adherence with ART in the prison setting; this barrier was associated with the logistics of movement in the prison and KOP and DOT. She quite clearly defined the issues as she viewed them:

> I had a few problems. I had, I had surgery and it takes days to get your medicines. Go to lock up, you don't get your medicine. Anytime they have to package up your property, from your locker, there is a chance you won't get your medicines. There is usually a delay in getting your medicines. If you get transferred from one camp to another camp, you might have a problem. Person gets locked down for a riot or a storm or anything, there is a possibility of problems with DOT. Sometimes there aren't enough nurses to give out the meds. PRN replacement takes time, really a lot of time. . .charts are lost.

Janet calls for the prison health system "to be overhauled" to make adjustments for medication adherence if an inmate is in lock up or the facility is in lock down.

Facilitators for adherence

The women interviewed had many examples of facilitators to ART adherence. The majority felt the routine in prison made obtaining and taking ART easier. Laura, a 34-year-old Caucasian woman who had been HIV positive since 2003 and on ART 1 month, explained the advantages of routine, "Taking my medicines between 9:30 and 10 o'clock every night (pause) the lights go out at 9:30 so I have my medicines out and I know it is time because the lights go out. It helps me remember to take my medicine." The reliable refills and access to regular refills in prison was given as a means facilitating obtaining ART. The med call helped remind the inmate to take medications and was especially facilitated when the nurses, friends or officers reminded the woman to take her medications.

Seven of the women advocated KOP as the best way to encourage adherence. Being in control, easier access, and not having to wait to take medications were examples of how KOP facilitated ART adherence. Carmen, a 39-year-old Latina woman had been HIV positive for 15 years and received her medications by DOT. She had a history of a

stroke with residual memory problems and spoke in a deliberate, monotone manner. She gave one-word answers for the most part until asked what changes she would make in medication administration. Carmen clearly stated, "Giving them to myself…Keep the medicines here." This was not a realistic option for her, but her comments were re-iterated by the majority of those interviewed.

Two of the women found DOT helpful in both obtaining and taking ART. Jackie, a 40-year-old African American woman, had HIV since 1999 and had been on ART for 3 months with this incarceration. She took two medications independently and one was administered by DOT. Jackie liked the routine medical visits and opportunity to receive regular refills. She seemed surprised by the question regarding changes in the prison medication system, "Well, wow! Well (pause) DOT (pause) I think it's given in the right way. . . Some need to be watched, some don't. I would not change." She liked the contact with the nurses as well as having some independence in her self-care. Lisa, a 34-year-old African American woman, had been HIV positive since 2001 and on ART for two months. Lisa liked DOT because she got her medications on time and felt better. She talked about the benefits of having the nurse watch her take her medications and having the officers call her for med call. Dorothy saw benefits of both KOP and DOT. Dorothy said

> Keeping my own medications, make you feel good, proud when you take your meds. You know what I'm saying? DOT is good too. To make sure you are taking them. Both keeping it and having DOT is good because you don't want to keep *all* your meds."

The women talked about less visible facilitators for adherence when they spoke of "a will to live." Acknowledging the disease and learning more about their health made

acceptance of ART easier. Jackie noted, "I understand how imperative it is to take your medicines. Not missing any and taking it more seriously as far as taking care of yourself (sic)." Laura had similar sentiments when she said, "I take care of myself…when I take my meds." Adherence was improved when their health was taken more seriously. Lisa thought the prison was doing a good job with her DOT administration because, with regular medication therapy, her health had improved. Maria expressed fear her CD4 counts would drop and felt appointments once a month to evaluate CD4 and viral load would be beneficial. For those who had been in denial and not taking ART, acceptance of their HIV status helped them be adherent with ART.

The majority of the women discussed how having fresh medications (unexpired) and access to refills (PRN slips) helped them acquire ART in prison. Two mentioned when they needed a refill, the nurse had already requested it for them and the new medications were waiting in the infirmary for them. Nine of the women did not take medications outside of prison – most did not elaborate on why, but liked staying "up to date" on the medications while incarcerated.

Healthcare provider relationships and adherence

All the women except Kristie specifically mentioned their relationship with healthcare providers in prison. The relationship could be a barrier or a facilitator to adherence depending on their experience. Laura, Jackie, Maria and Monique enjoyed talking with the chronic disease nurse and felt this relationship supported them in adherence. Carmen, Angela, Jackie and Lisa felt the nurses were reliable and facilitated distribution of medications. Carmen said she could talk with the nurse about side effects. Angela felt the nurses could be relied on and expedited the refill process. Jackie found the

chronic disease nurse was approachable and helped solve problems related to medications. Lisa remarked the nurses were patient and helpful with DOT and making sure she made med call.

Conversely, Dorothy's experience with the nurses was very different. She said the nurses do not listen and might talk about the medications where others could hear them. Barbara did not like waiting for the nurses and thought the wait impeded adherence. Janet complained there were not enough nurses; they "can be hard-pressed" and she felt this slowed down the distribution of medications. Janet's experience with the nurses made her feel the nurses needed "more compassion" and wanted the nurses to treat inmates better – "treat you like you matter." She said, "It hurts" being treated like you "don't matter."

The women had varying experiences with the doctors. Carmen said the doctors were "no good." Meanwhile, Dorothy said, "you can count on" the doctors. Jackie felt the doctors helped make it easier to get ART. Talking about her doctor, Jackie said, "She's real good, easy to relate with." Being comfortable talking to the doctor helped Jackie, Maria and Lisa adhere. Officers who "looked out for you" and reminded inmates of med call helped with taking medications regularly. Jane said the officers could help or hinder medication adherence based on if they helped an inmate get from one place to the medication line. Lisa found the officers who let her know when it was medication time helped her adhere. It was important for healthcare providers (nurses, doctors, officers) to listen and help the women with acquisition of medications in addition to listening and problem-solving adherence issues.

Medical privacy and adherence

Seven of the participants had comments about privacy and ART. Monique, a 35-year-old African American woman had been diagnosed with HIV since 1996, and was adamant the privacy and independence of KOP made adherence possible for her. She stated several times of "loving giving it myself" and being responsible for herself. Monique explained she had been in denial before coming to prison about her HIV status, but, with psychiatric help, she was feeling better about herself and enjoyed being in control of her health.

Maria liked the privacy of KOP, "Let the ladies keep their own medications." Dorothy was again the most verbal about privacy. She liked KOP but felt KOP presented a potential for dorm-mates to learn of your status if they saw you with your medications. She thought DOT probably was more private after talking about the assumptions other inmates make based on the number of pills taken. Dorothy was offended when nurses talked about the medications she was taking in the medication line in front of others. Angela had issues with the bottle medications were dispensed in, thinking it was a violation of her privacy if only HIV medications came in the white bottle. Jane wanted a separate place for HIV dispensing – but not for privacy reasons. Jane wanted more efficiency in dispensing and did not mention concern over a breach in confidentiality. Most women wanted medications given in a manner that prevented others from learning their HIV status and the nature of their medications.

CHAPTER FIVE

DISCUSSION

The purpose of the study was to describe the perceptions of HIV positive incarcerated women regarding barriers and facilitators to ART adherence, the role of healthcare provider relationships with adherence and how medical privacy influences adherence. Male and female inmates have been critical of healthcare while incarcerated and have sought legal protection for perceived injustices in the prison healthcare system (Palmer & Palmer, 2004). A prisoner's right to healthcare was legally established by the United States Supreme Court decision *Estelle v. Gamble* (1976). Women's healthcare in the prison system is often made more difficult than men's healthcare due to prison regulations, logistics of moving from dorm to infirmary and lack of full service healthcare (Stoller, 2003). Incarcerated women use sick call more frequently and often enter the prison system with healthcare needs that were not met before incarceration (Young, 2000). Meeting the special healthcare needs of incarcerated women can be challenging with the limited resources most prisons experience (Spaulding, et al., 2002). Living with HIV and taking ART while in prison is best described by those experiencing the phenomenon and can provide the necessary understanding required for planning interventions to improve adherence with ART.

What are the barriers to ART adherence?

The necessarily coercive nature of the prison setting results in lines that, while orderly, have little regard for efficiency or privacy. Inmates have little choice, as there are not

multiple lines from which to choose for the service sought. Prisons have set times for medication administration and the prisoners are called to the medication line by correctional officers; arriving to wait their turn (Spaulding et al., 2002). The medication line, with the frustration of waiting and perceived visibility to others, was a prevalent concern for the women in this study. Several authors have found those who receive ART by DOT often complain of the inconvenience, loss of privacy and intrusiveness of DOT (Lucas, Flexner, & Moore, 2002; Santos, Adeyemi & Tenorio, 2006; White et al., 2006; Wohl, et al., 2003). The women in this study, even those who did not receive ART via DOT, clearly saw the difficulties of dependence on the system for timely medication administration. This implies an understanding of the gravity of the need for close adherence and advocates for KOP. Based on the comments by nine of the twelve participants, having control over one's own medications afforded some small self-determination in the prison world where choice is not an option or a goal. However, three women saw value in DOT for ART administration and one woman saw advantages in both KOP and DOT.

Stigma was thought to be lessening as treatment progressed and HIV became less a death-sentence and more chronic in nature (Lekas, Siegel & Schrimshaw, 2006). According to the women in this study, stigma continues to be of concern and a detriment to adherence. Stigma indicates loss of value, dehumanization or worthlessness to others (Pryor, Reeder, Yeadon, & Hesson-McInnis, 2004). Many of these women faced multiple stigmata including incarceration, positive HIV status, being a drug user and/or homeless and having mental illness (Ware, Wyatt, & Tugenberg, 2006). Prisoners are seen as dirty or dangerous by others (Glaser & Greifinger, 1993). HIV and people with HIV continue to be feared by the public (Lekas, Siegel & Schrimshaw, 2006). The stigma of being treated differently, less

compassionately and even "mean," was a result of DOT (being viewed in the line more frequently or with large numbers of pills) and KOP (dorm-mates questioning number and type of medications.) Stigma creates a sense of loneliness and hopelessness associated with decreased adherence (Rintmaki, et al., 2006; Sandelowski & Barroso, 2004; Ware, Wyatt, & Tugenberg, 2006). As indicated by these women, limiting stigma through protecting HIV status from others was viewed as desirable and enhanced ability to adhere.

Angela's comments regarding her perception that only HIV medications come in white bottles was interesting. In my experience, rumors and gossip fuel false perceptions in the prison setting and Angela offers a prime example, as white bottles are used for all medications; however her perception was that only HIV medications were dispensed in white bottles. True or not, this perception made her feel her status was open to any who saw the medication bottle. Stigma has been found to occur as a dual-process response – one in which the person reacts in both a conscious and unconscious manner (Pryor, Reeder, Yeadon, & Hesson-McInnis, 2004). The dual-process response to HIV manifests as an impulsive reaction towards the HIV positive person as well as in a controlled manner with deliberate actions. These dual responses are learned from the culture surrounding the person (Pryor, Reeder, Yeadon, & Hesson-McInnis, 2004). Data from the interviews illustrated the reflexive reaction (assumption based on number of medications and being in the line) and subsequent deliberate actions (attitude and poor treatment) against the HIV positive woman in prison.

Prison policy results in the third major barrier concerning these women. The loss of medications during lock downs and lock ups, though usually temporary, disrupted adherence and served as another source of frustration. Security necessitates the close control of inmate movement when storms or rioting occurs. An inmate who requires lock up – often for

violation of the rules such as not fighting, cannot have personal belongings while sequestered; however, medications necessary for sustaining life (diabetes medications, for example) are not withheld; but are given as DOT for safety reasons (Blanco, Perez, & March, 2005; Spaulding, et al., 2002). Janet's complaints about transfers from prison have some validity as there can be a transfer of an inmate to another prison (called a camp) with little to no warning. The women's belongings are packaged and sent to the new prison where processing and inspecting may delay the inmate receiving her KOP medications and personal effects. However, because there are limited resources in this state's prison system, the prison used in this study is the only one in the state that houses pregnant women or HIV positive women. Therefore, ART would not be disrupted by a transfer because the HIV positive woman would not be transferred. What appears to be a random transfer of a woman to another facility, most likely is necessary to make space for a woman who cannot be housed at another prison. Shortage of staff capable of administering ART presents another challenge for prison medication administration (Lucas, Flexner, & Moore, 2006). Although short-staffing issues were recognized, the women wanted access to their medications during lock down as a means to continue their therapy as prescribed. Additionally, DOT presented problems if the woman, while at another appointment, missed the med call. With little flexibility in medication administration times, even understandably so, a missed opportunity presents a problem of non-adherence for many.

What are the facilitators for adherence?

The answer to improved adherence, repeated by most of the women, was KOP. The sense of pride and responsibility not only improved self-esteem, but also gave the women a reason to adhere. White and colleagues (2006) had similar findings in their study where the

majority of their participants preferred KOP. For the women in this study, KOP avoided the "hassle" of the line and had the potential to be more private. KOP additionally offered a chance for self-determination in a setting where the inmate has little choice or control over their daily routine.

Before DOT is totally discounted, however, note that there was support for DOT by the women in this study. Some women felt DOT helped them, by offering routine and an opportunity to talk with a nurse. It was recognized that some people benefit by DOT, where others could handle KOP effectively. The women who saw benefits of both types of administration were advocating for individualized treatment plans. Additional adherence facilitators were described as a concern for health, a desire to live and evidence of improved health by increased CD4 counts. Several comments about having access to refills and fresh (non-expired) medications indicate supply of ART in prison is advantageous to adherence. With the prevalence of comments about having ready access and since few (three of the twelve) took ART out of prison, it suggests access to medications on the outside is problematic. Jane, who was concerned with being first in line to get her ART, became emotional and was crying when asked about taking ART when not in prison. She found the "red tape" and referral from doctor to doctor difficult – "I lost my pride…this disease is not easy." Thus, the structure of the prison can be a positive factor influencing adherence.

Healthcare provider relationships and adherence

The women emphasized the importance of a comfortable relationship with the healthcare provider while incarcerated. The chronic disease nurse, the physicians and sympathetic officers were given as support for receiving and taking ART. The ability to ask questions and feel their concerns were heard improved the women's ability to take ART.

Poor relationships, such as feeling the staff were uncaring or unsympathetic, hindered receiving and taking ART. There were several comments related to nursing care as a barrier to adherence, but an understanding of the staffing issues in prisons should be noted. Based on my observations and those of my committee members with experience in prison healthcare (Drs. Fogel, White and Fishel), there can be great variability in the educational preparation of staff dispensing medications to inmates. Due to enormous turn over rates, the prison often employs medication technicians rather than licensed nurses; however, most inmates do not distinguish the difference (all are "nurses"). I suspect many of the comments regarding uncaring nurses may actually be referring to medication technicians. The staff (nurses and technicians alike) are often burned out and overburdened in a system that is frequently under-manned. Licensed nurses are usually placed in the clinics, taking sick calls and tending those in the infirmary. Medication technicians therefore tend to dispense ART at the medication window and often appear rushed, emotionally distant and even disrespectful or rude. The situation illustrates the advantages of a fully licensed staff with adequate numbers and education to provide professional care.

Individualized care and support for adherence from a physician were found to enhance ART adherence outside of prison (Beach, Keruly, & Moore, 2006; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004). Indications from this study suggest individualized care and physician support enhances ART adherence while incarcerated too. The chronic disease nurse was viewed as someone that could help problem-solve side effects of the medications and an approachable person. Young (2000) interviewed incarcerated women about general healthcare finding the most positive experiences were related to being treated

as an individual with caring and compassionate attention from the healthcare providers. The women with HIV in this study were no different.

Medical privacy and adherence

With the majority of the women interviewed in this study expressing varying degrees of concern for loss of medical privacy, privacy was indeed discussed as a barrier to adherence for the women. Whether the fear of labeling and stigma associated with others finding out HIV status, or being treated differently, the loss of privacy was painful and detrimental to adherence. White and associates (2006) acknowledged the problems with DOT and loss of privacy potentially reducing adherence for inmates. Wohl and colleagues (2003) found the loss of confidentiality made KOP the preferred ART administration method, especially when correction officers were privy to medical information when dispensing medications in the absence of medical staff.

Because no studies that specifically addressed medical privacy and adherence for inmates were found, the concerns expressed by the women participating in this study become especially important. Based on the comments by the women here, medical privacy is a desired privilege. There is no legal provision in the United States Constitution for medical privacy; however, nurses could advocate for prison policy changes that would protect medical information for all inmates. It is not realistic to simply prescribe KOP for all women. Carmen is a prime example of someone who, due to her history of a cerebral vascular accident (stroke) and subsequent short-term memory impairment, would be unable to reliably administer ART medications properly to herself. Some of the measures used to protect medical information in the private sector could work in prison. Discrete dispensing windows, an area for private counseling and covered or shielded medication bottles are a few examples

employed in pharmacies that could work in prisons. Education of all staff, medical and correctional, to dispel myths, improve general knowledge and understanding would reduce stigma (Arriola, Braithwaite, & Newkirk, 2006). Education for medical staff ensures adequate training to counsel HIV positive people (Tugenberg, Li, Ware, & Wyatt, 2006). Further, education for the women here improved their willingness to adhere to ART and created a sense of pride when they realized they were behaving in a manner that improved their health.

Conclusions

After spending considerable amounts of time with both listening to the interviews and re-reading the transcripts and field notes, I feel as if, in some way, I was present for the interviews. As I read a transcript, I could hear the woman's voice, and remembered the inflections as she spoke. For this reason, I believe a researcher conducting a secondary analysis in this manner, can, to some extent, become part of the interaction – deriving impressions and feelings from both the written transcripts and listening to the women speak. Even for the researcher who collected the interviews personally, repetitive review greatly enhances understanding and improves the validity of findings (Heaton, 2004; Mason, 2004; Ryan & Bernard, 2003; Sandelowski, 1993). Sensitivity to the context of the interviews and developing the sense of presence within the interview was accomplished in this secondary analysis (Hinds, Vogel, & Clarke-Steffen, 1997; Szabo & Strang, 1997).

HIV positive women who are incarcerated represent a unique population that is growing in numbers annually. The women in this study described pertinent barriers and facilitators to adherence while incarcerated. Interventions to increase the positive influences and reduce the negative influences on ART adherence are certainly possible at this point. In

summary, the factors influencing ART adherence defined by the women interviewed were the medication line, stigma, the routine (regular administration times and access to medications), administration choice (directly observed therapy or keep own prescription), a relationship with the healthcare provider, the policies within the prison, receiving education about the disease and medical privacy.

Future work should explore the process of changing prison medication administration policy to incorporate choice in ART administration method (when medically reasonable). Steps to protect the privacy of HIV positive inmates could include providing screened dispensing windows for all medication administration using DOT and use of generic labels for the medication bottles used with KOP. Education of all prison staff with current knowledge about HIV transmission and treatment goals may improve interaction with HIV positive inmates and has the potential to establish rapport that improved adherence with ART. It would be desirable to lobby for state and federal support for trained nurses to administer medications versus the medication technicians and correctional officers. The women in this study were desirous of a relationship with a knowledgeable healthcare provider. Medication technicians and correctional officers simply do not have the necessary training to provide this service. An investigation into the feasibility of keeping ART available, on schedule during lock downs and lock up is needed as a means to continue scheduled ART.

The women in this study live with HIV and understand better than others what it is to be adherent with ART while incarcerated. Dorothy said, “I care more about my health than what some think.” I believe every woman in this study would agree with her statement and would be willing to help nurses improve the lives of incarcerated women with HIV.

Limitations

The major limitation of this study was the inability to clarify or further question the inmate on her answers to the initial interview question. Although not present for the interviews, I found being able to listen and re-listen to the tapes invaluable. The study was based on one prison, but the prison used is similar to other large prisons providing healthcare to the HIV positive female inmate. Furthermore, it would have been helpful to know more about the women who refused participation to assist in determining the motivation or underlying reasons to decline research participation in such a population.

Future directions

This set of interviews used for the qualitative exploratory, descriptive inquiry contains more important information about the role of support persons in adherence and how the women perceive their health and HIV status since incarceration. Certainly further secondary analysis is possible and needed. Additionally, the information found in this analysis will be shared with the prison warden and officials for their review. Possible interventional studies aimed at creation of a screening tool to evaluate which women would be suited for KOP, education programs for staff and officers about HIV and adherence and perhaps, implementation of a campaign to guarantee medical privacy for inmates are a few of the potential results of this study.

Future interventional studies should consider the key elements defined by this study – modest allowances for inmate input into their medication administration method, protection of the medical information for each inmate, methods to foster the professional relationship between the inmate and the healthcare providers and education for both inmates and the correctional staff aimed at reducing stigma.

Appendix I

Subject _____, interviewed _____ at _____

(I) When were you first told that you were infected with HIV?
(P)

(I) Was this diagnosis made in prison?
(P)

(I) Have you ever lived outside of prison since you were first told you had HIV?
(P)

(I) How long have you been in prison for your current sentence?
(P)

(I) How many times have you been in prison?
(P)

(I) How old were you the first time you went to prison?
(P)

(I) Over the years, how much time have you spent in prison?
(P)

(I) How long have you been treated for HIV in prison (include prior incarcerations)?
(P)

(I) When did you first begin taking medications for HIV?
(P)
(I) Please list the HIV (Anti-retroviral) medications you are currently taking, not counting any changes made today.
(P)

(I) Do you either: Keep your medicines (KOP) and take them yourself, go to the medication line and take your medicines in front of nurse/correctional officer for your medications (DOT) or both
(P)

(I) Tell me about taking medications in prison?
(P)

(I) Do you ever have difficulties getting medications in prison?
(P)

(I) Do you ever have difficulties taking medications in prison?
(P)

(I) Are there things that make it easier for you or help you get your medications in prison?
(P)

(I) Please list some thing that make it easier for you or help you get your medications in prison.
(P)

(I) Are there thing that make it easier for you or help you take your medications in prison?
(P)

(I) Please list some things that make it easier for you or help you take your medications in prison
(P)

(I) Do your medications ever make you sick or not feel good?
(P)

(I)Now I am going to ask you some questions about support that is available to you
(I) About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?
(P)

(I) Is there anyone in prison who you rely on to help you take your HIV medications in prison?
(P)

(I) Please list for me ways that these people/this person helps you to take your HIV medications in prison?
(P)

(I) Is there anyone in prison who makes it difficult for you to take your HIV medications in prison?
(P)

(I) Compared to 12 months ago, has your overall health: gotten better, remained the same or gotten worse
(P)

(I) Can you list for me some reasons why you think your overall health has changed in the past 12 months?
(P

(I) Compared to 12 months ago, has your health related to HIV: gotten better, remained the same, gotten worse?
(P)

(I) Can you list for me some reasons why you think your health related to HIV has changed in the past 12 months?
(P)

(I) If you could make changes in how medications are given in prison, please list the changes you would make.
(P)

(I) Now I am going to ask you questions about what it was like to treat HIV before prison

(I) What was is like taking medications before prison?
(P)

(I) did you ever have difficulty getting medications before prison?
(P)

(I) Did you have difficulty taking medications before prison?
(P)

(I) Are there things that made it easier for you or helped you get your medications before prison?
(P)

(I) Please list some things that made it easier for you or helped you get your medications before prison.

(I) Are there things that made it easier for you or helped you take your medications before prison?
(P)

(I) How old are you?
(P)

(I) Do you consider yourself Caucasian, African American, Hispanic or Asian?
(P)

(I) What is the highest grade or year of schooling you have completed
(P)

(I) How many people lived in your home before coming to prison?
(P)

(I) Were you receiving disability benefits, retirement benefits, working full-time, working part-time or unemployed before coming to prison?
(P)

(I) What type of work have you done most of your life (out of prison)?
(P)

(I) What was your household income before taxes, during the last year before you went to prison? Include income from all sources such as wages, salaries, social security or disability benefits, help from relatives, rent from property and so forth.
(P)

(I)Do you have any other comments about taking medications?
(P)

Additional interviewer notes:
General understanding of questions excellent good fair poor
Respondent was very cooperative, cooperative, or not cooperative
Felt patient was entirely honest somewhat honest
Sensitive about talking –

Additional relevant information

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